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Nurse Perspectives on Referrals for Oncology Patients to Reproductive Endocrinologists: Results of a Learning Activity

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Abstract

Background—For adolescents and young adults (AYAs) with cancer, concern about future fertility is widespread. Yet, referrals rates to reproductive endocrinologists (REI) are low. Oncology nurses are in a prime position to make these referrals but may lack the knowledge to do so. This report describes the results of a learning activity in the Educating Nurses about Reproductive Issues in Cancer Healthcare (ENRICH) program whereby oncology nurses interviewed REIs. The goal is to present how a learning activity can influence knowledge gained by oncology nurses from discussions with REIs about FP procedures, barriers, and facilitators for AYA patients

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Method—As one of two ENRICH learning assignments, participants were instructed to conduct an interview using a semi-structured guide and create a summary of responses. We examined responses to each question using qualitative content analysis.

Results—Seventy-seven participants (98% assignment completion rate) across 15 states provided a summary. Learner summaries highlighted four themes related to fertility preservation (FP), including cost, time, lack of information/referrals, and learning about available options.

Conclusion—Oncology nurses have a unique relationship and frequent interactions with AYA patients, thus placing them in a strategic position to educate about fertility and preservation. REIs are a critical partner to ensure all AYA oncology patients have considered current and future fertility.

Introduction

Adolescent and young adult (AYA) cancer patients have distinct medical and psychosocial needs compared to older adults, with reproductive health being a chief concern.(Bleyer A, Barr R et al. , Partridge AH, Gelber S et al. 2004, Schover LR 2009, Carter J, Penson R et al. 2011, Howard-Anderson J, Ganz PA et al. 2012) Available research suggests cancer-related loss of fertility can cause long-term distress and impaired quality of life in cancer survivors,(Canada AL and Schover LR) especially if patients did not receive sufficient information on fertility preservation (FP) options before the start of their treatment.(Gorman JR, Usita PM et al. 2011, Letourneau JM, Ebbel EE et al. 2012) Even 5–10 years after treatment, the grief associated with the inability to bear children or disruption of childbearing continues to impact survivors' quality of life.(Canada AL and Schover LR)

Several national guidelines including the American Society of Reproductive Medicine (ASRM)(ASRM, 2015) the American Society for Clinical Oncology (ASCO)(ASCO, 2015) and the National Comprehensive Cancer Center (NCCN)(NCCN, 2015) recommend referring AYA cancer patients to an REI as early in the treatment planning process as possible. Several surveys of adult and pediatric oncology providers demonstrate low levels of referral to an REI to discuss FP options (Quinn et al., 2009; Campbell 2016) A recent study reviewing medical charts of patients ages 18–45 treated in 2011 four large U.S. cancer care institutions found that 26% documented infertility risk discussion, 24% documented FP option discussion, and 13% documented referral to a fertility specialist (Quinn, 2015).

Oncology nurses are often expected to provide comprehensive assessments of patients and make appropriate referrals as necessary, including the area of FP (Loren et al., 2013; Vaartio-Rajalin & Leino-Kilpi, 2011). In a single-site study, an oncology nurse education program increased FP referrals by 71% (Clark, 2013). Less is known about the quality of these referrals. It is important for nurses to not only have the awareness to make a referral, but to understand the details of the services offered in these clinics. Few programs exist that provide this information and can be accessed by large numbers of nurses from diverse clinical and geographical practice settings.

This purpose of the current study is to describe the results of an the learning assignment within the ENRICH training program where nurses contacted an REI for an interview to

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gain knowledge about the process of and procedures associated with FP. Specifically, we report on themes that emerged as a result of reviewing nurse reflections about the discussions they engaged in with REIs. The goal is to present how a learning activity can influence knowledge gained by oncology nurses from discussions with REIs about FP procedures, barriers, and facilitators for AYA patients

Methods

Curriculum Development

This project was deemed exempt by the University of South Florida Institutional Review Board on the basis that it involves evaluation of an educational program, Category 1 in the Code of Federal Regulations (45 CFR 46.101 b). The development of the training program is detailed elsewhere (Vadaparampil, 2013). In brief, over the course of 8 weeks, nurses completed a series of 6 content modules and 2 skill building modules comprised of narrated PowerPoint presentations delivered by national experts via pre-recorded, narrated power-points, readings from the course textbook, and case studies. The first half of the modules primarily focused on infertility and FP options including: (1) male reproductive health and cancer; (2) female reproductive health and cancer; (3) pediatrics and reproductive health; (4) FP options. Two modules covered other reproductive issues: (5) sexuality (6) alternative family building options. The last two focused on skill building specific to discussion of infertility and FP options including (7) communication skills training where a fertility nurse specialist modeled discussions regarding fertility and FP with a male and female standardized patient; and (8) practical applications where a fertility navigator discussed strategies to overcome institutional, systems, and financial barriers to FP. Ethical, legal, and psychosocial considerations of reproductive health were infused throughout all modules. Learners participated at their own pace.

The overall program was based on principles of adult learning theory including: (1) learning should capitalize on the experience of the participants, (2) learning should be adapted to the limitations of the participant, (3) adults should be challenged to move to advanced stages of personal development, and (4) adults should have choice in organizing the learning program (Cross, 1981). Thus, nurses also completed learning assignments focused on interviewing an adoption agency (Quinn, 2015) and a local reproductive endocrinologist. These activities were designed to enhance nurses' existing knowledge gained from the didactic portions of the training program to include practical knowledge related to identifying and facilitating various options for family building. In addition, by having them identify and contact a local agency or REI of their choice, participants also practiced the steps that would be similar to identify these resources for their patients. It is also possible that this initial interaction may facilitate future comfort and confidence in approaching the same or similar types of entities/ providers on behalf of patients seeking these options.

Recruitment and Application Process

Minimum qualifications for ENRICH program participation included having a Registered Nurse (RN) license and providing care for at least 5 AYA patients per year. Nurses were recruited through a variety of approaches, including: nominations by training program

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teams, conference promotions, emails through nursing professional organizations, nurse training program alumni associations, and a Children's Oncology Group newsletter. Those interested in participation completed an application with basic education and practice information, a brief personal statement including a plan for applying their ENRICH training to improve practice at their institution, and a supervisor's recommendation. The training program team reviewed applications and notified applicants of their acceptance approximately 6 weeks before the course start date.

REI Interview Assignment

Participants completed the course at their own pace within the 8 weeks allotted for the training program; however, they were required to complete the course in sequence and could only move from one module to the next after completing all previous module components. The average time commitment was ~60–90 minutes per module. Nurses completing all course requirements received 11 Continuing Nursing Education (CNE) credits.

As part of their involvement in the training program, learners who participated in ENRICH from January to March 2014 were instructed to identify an REI (local, state, or national). They were provided with a broad set of instructions at the beginning of the course to identify an REI with whom they could conduct a telephone interview. Nurses received weekly electronic reminders leading up to the due date (week 7) to ensure timely completion of the assignment. The completed assignments were uploaded using an electronic learning management system, Learndash, similar to those used for on-line academic courses at universities. These assignments were considered to be a required component for award of CNE credits in March 2014 and were therefore reviewed for completeness by the study research coordinator.

Similar to "real-world" clinical scenarios, nurses were expected to use their own skills and knowledge of their geographical practice setting to identify REIs, although the team was available as a resource to assist nurses encountering difficulty in identifying an REI. They were provided a series of sample questions, in the form of a semi-structured interview guide, to ask the REI including:

- On average, how many cancer patients do you see per year?
- Do you provide initial consultations to cancer patients over the phone?
- What is the best way to schedule a consult for a cancer patient?
- What are the fees involved for IVF? Cryopreservation services?

Following the interview, learners were instructed to write a personal reflection summarizing the interview guided by three interview content domains: 1) What are some challenges you think cancer patients may face in addressing REI services?; 2) What information provided by the REI was most surprising to you?; and 3) What changes could you make in your practice setting (if any) to facilitate patient access to REI services? (Table 1)

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Data Analysis

Using an inductive approach to qualitative content analysis, two trained research assistants examined all responses to each question and utilized the interview probes to develop an *a priori* code list to organize the data (Table 1). As described by Miles and Huberman (1994), coding procedures involved examining each individual response and assigning it a label (code) to represent the content of the response. Inter-rater reliability for this procedure was 95%; discrepancies were addressed and discussed by the reviewers in consultation with the senior author. Through a process of constant comparative analysis (Corbin & Strauss, 1990), coded responses were organized into thematic categories. The intent of this analysis was to obtain meaningful and diverse information rather than to quantify the preponderance of responses (Corbin & Strauss, 1990). The goal was to present the scope and depth of knowledge gained by oncology nurses from discussions with REIs about FP procedures, barriers, and facilitators for AYA patients

Findings

Seventy-seven participants (98% assignment completion rate) across 15 states provided an interview summary. As shown in Table 2, the vast majority of learners were White, non-Hispanic, female, and had at least a bachelor's degree. Close to half worked at an academic cancer center and about one third had between 1 to 10 years of experience in the field of nursing. Qualitative analysis of the nurse-learners summaries identified four overarching themes: 1) concerns about cost, 2) challenges to timeliness, 3) lack of information and referrals for patients, and 4) learning about options available, especially for female AYA populations. Illustrative quotes relating to themes are displayed in Table 3.

Concerns about Cost

The most frequently reported finding from ENRICH learners was learning REIs identified cost as the biggest challenge cancer patients face in accessing REI services, mostly due to lack of insurance coverage. This finding was surprising to all learners. Half of the participants learned about reduced-cost and free FP options from the REIs they interviewed. Another participant reported that despite available FP resources to assist with financial burdens, patients must meet certain requirements for aid and complete extensive paperwork, which can be a barrier in itself for some patients as reported by one learner.

Challenges to Timeliness

The second most frequently reported learning topic was the importance of timing in the referral process. The need to initiate treatment shortly after diagnosis presents a barrier to both patients and providers when discussing FP options. A majority of learners reported that the REIs they interviewed felt oncologists were "*not programmed*" to consider postponing treatment for FP due to a sense of urgency and pressure to begin cancer treatment immediately. Risk to fertility was not considered a priority when the main focus was on treatment and survival.

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Lack of Information and Referrals for Patients

Nearly all of ENRICH learners reported that the REIs they interviewed suggested oncology patients do not receive appropriate fertility information or resources from their providers, making these patients unlikely to pursue FP prior to treatment. At least half of the learners reported REIs indicated patients may not be thinking about the impact of treatment on fertility or may have misperceptions about fertility and oncology. Several learners noted their REIs interviewees commented on the low number of cancer patients referred to REIs despite the larger number of cancer centers within close proximity. Some REIs told nurse learners they felt REI referral from oncologists to be one of cancer patient's most difficult challenges in terms of accessing REI services. Providing resource and referral information was one of the most frequently cited changes ENRICH learners felt could be made in their practice settings to facilitate patient access to REI services.

Learning about Available Options

Another important theme reported by the majority of nurses was the awareness and availability of FP options. Many of the REIs suggested that oncologists may be unaware of many aspects of REI that are relevant to cancer patients. Nurses reported they were surprised by current FP technology and were unaware of some of the options available to patients. Most learners felt that staff education was top priority to increase provider conversation comfort level, to improve awareness and knowledge of FP, and to standardize fertility discussions.

Of particular interest were population-specific FP options. REIs identified the provision of FP-related services and discussions as a major barrier for younger AYA patients. Specific barriers for AYA patients included providing appropriate material for younger males regarding sperm collection, availability of FP options for younger patients, and parental involvement.

Initiating a discussion about future family and children with newly-diagnosed young patients can be especially challenging if the patient lacks basic reproductive knowledge and has not yet considered future family planning. For those who may not yet be thinking of future children at the time of diagnosis, FP may not be perceived as a priority over initiating cancer treatment. Nurse participants learned this is often true for parents of pediatric patients, who may be particularly sensitive to the urgency of treatment initiation.

A majority of nurses reported REIs mentioned multiple ways in which FP services may be more challenging for female patients. Barriers included higher FP costs, longer time delays, and more complex procedures, which some patients may believe will negatively affect their outcomes.

In terms of cost and timing, female patients face higher costs for FP services and storage fees, as well as longer treatment delays–even if the time delay is relatively short, e.g., two to three weeks—as compared to men. Overall, ENRICH learners gained perspective on the FP concerns faced by different populations from interviews with REIs.

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Discussion

While discussing barriers and facilitators to FP for AYA oncology patients with REIs, nurses learned that most of the REIs interviewed received few patient referrals from oncology providers directly; most oncology patients sought referrals on their own. This appears to support the findings from several studies focused on oncologists that demonstrate both low rates of self-reported (Bastings et al., 2014; Goodman et al., 2012; Quinn et al., 2009) and chart-documented referral (Quinn et al., 2015). This study summarizes some of the potential reasons that discussion about and referral for FP are challenging. By completing this assignment nurses were able to integrate the information shared by REIs and improve their understanding of critical issues relevant to FP for AYA oncology patients including: 1) concerns about cost, 2) challenges to timeliness, 3) lack of information and referrals for patients, and 4) learning about options available, especially for special populations (e.g., females, AYA).

With regard to the cost of FP, the majority of nurses in the ENRICH learning program reported gaining more nuanced knowledge and understanding. Despite the high cost of FP, conversations with REIs shed light on the availability of low-cost and free FP options available through LIVESTRONG and other financial assistance programs. Many nurses also reported being surprised to learn about payment plans offered by many of the REIs they interviewed. Realizing REIs are aware of and willing to work with patients to overcome cost as a barrier to FP appeared to make nurses more confident when referring patients for FP. Another piece of information that was surprising to learners was that FP was, in general, not covered by insurance. Findings from this assignment highlight the importance of moving beyond providing information about financial costs of FP to exploring the range of financial assistance options available for patients as well as advocating for policy change as it relates to FP insurance coverage for cancer patients.

The majority of ENRICH learners reported changes in their perceptions of competing priorities for reproductive preservation referral. While the timing of FP is critical, the majority of REIs explained to nurses that treatment can be safely delayed in many situations if expedited stimulation protocols are not available. Conversations with REIs broadened learners' understanding of time constraints, as well as available windows of opportunity for nurses to collaborate with REIs and other members of the oncology care team to facilitate FP for patients. This activity also facilitated participants acquiring skills in consulting other professionals. Awareness of windows of opportunity for FP contingent upon patient and treatment characteristics affords oncology nurses the ability to provide better information and more reassurance to patients.

Through the interviews, ENRICH learners also found that REIs recognize the challenges oncology providers face in discussing FP options with patients, specifically relating to discomfort with the specific information that needs to be provided. In particular, the nurses reported that REIs are willing to provide the FP consultation, but suggested that a systematic approach to identification and referral of patients is needed.(Johnson & Kroon, 2013; Loren et al., 2013; Quinn et al., 2011) One example of this is offered in the ASCO guidelines and at least two institutions have reported on the process developed. The nurses participating in

ENRICH seemed eager to make these changes at their workplace by way of communicating reproductive health and FP topics with patients and families and collaborating with other members of the oncology care team.

ENRICH nurses will be instrumental in providing FP referrals for patients and creating relationships with REIs to provide the needed information. Finally, ENRICH learners indicated the field has advanced rapidly and there is a need to keep oncology care providers informed, particularly regarding the issues and options for specific populations. The results also indicate that bringing up these difficult issues is challenging due to concerns about cost, timeliness, lack of information and referrals for patients, and availability of FP options. One solution proposed by ENRICH learners is to more directly involve REIs at all levels of professional education and training in the oncology care community. Some examples provided by our learners included having REI speakers at national conferences as well as local grand rounds presentations.

While this study is among the first to report on discussions between nurses and REIs about referral of AYA oncology patients, results should be considered in light of certain limitations. First, the data presented were reported in written summary form by the nurses as part of a learning assignment. Therefore, it is possible that the content of the summaries did not capture all comments and perspectives from the REIs they interviewed. Second, we did not have information on the characteristics of the REIs interviewed to assess the diversity of perspectives and practice patterns represented (e.g., academic vs. private practice, gender etc.). Finally, these interviews were conducted with REIs representing 15 U.S. states and it is possible that there is state level practice variation that may not be included in our sample. Although the results cannot be generalized, they can be used to guide future initiatives and training programs. Our findings show that working professionals were willing and able to complete a learning activity that may facilitate future referral for clinical care of their patients. Educators offering continuing education opportunities and graduate programs for nurses may consider making such activities a possible component for future programs in any context where inter professional collaboration may be required.

Conclusion

Oncology nurses have a unique relationship and frequent interactions with patients, thus placing them in a strategic position to engage in subsequent conversations about fertility. REIs are a critical partner in ensuring that all patients receive accurate and timely consultations and FP treatments regarding their future fertility. Barriers such as concerns about cost, treatment delay, comfort in providing information about FP, and communication challenges among oncology nurses have been previously identified as barriers to discussion of FP with AYA patients.(Clayton et al., 2008; King et al., 2008; Lester, Wessels, & Jung, 2014; Vadaparampil et al., 2007; Wallace et al., 2015) This assignment provided nurses the opportunity to hear directly from REIs about their perceived challenges in ensuring timely access to the services they provide. In addition, the nurses learned about REI willingness to facilitate these services by helping patients and providers overcome barriers related to costs, timing, and knowledge that likely influence limited use of these services. While our findings are encouraging, next steps involve evaluating whether the overall program has resulted in

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practice changes among the participants, including the development of partnerships with local REIs to facilitate AYA access to FP services.

As part of the successful ENRICH program, this REI interview assignment provided nurses the opportunity to hear directly from REIs about their perceived challenges in ensuring timely access to the services they provide. Nurses learned about REI willingness to facilitate these services by helping patients and providers overcome barriers related to costs, timing, and knowledge that likely influence limited use of these services. Additionally, nurses were able to develop relationships with local REIs for potential future partnerships. ENRICH nurses will be instrumental in providing FP referrals for patients and creating relationships with REIs to provide the needed information. With rapid advancements in the field, there is a need to keep oncology care providers informed about FP options for cancer patients, particularly regarding specific populations with unique needs.

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Table 1

Interview Content Domains

Reflection Question	Code Defined
➢What are some challenges you think cancer patients may face in addressing REI services?	• Cost • Time Constraints • Adolescent and Young Adult (AYA) cancer survivors • More Difficult for Females • No Information or Resources Available • Not a Priority • Emotional/Mental Health • Ethical Concerns • FP Failure Rates • Hormone Treatment • Lack of Access • Lack of Provider Knowledge • Lack of REI Referrals
➢What information provided by the REI was most surprising to you?	• FP Options Available • Low Number of Cancer Patients Seen by REI • Costs • FP Failure Rates • Preimplantation Genetic Diagnosis • Legal Issues with Surrogacy • Reduced-Cost/Free Options
➢What changes could you make in you practice setting (if any) to facilitate patient access to REI services?	• Staff Education • Patient Education • Earlier Discussions • Providing Resources • Increasing REI Referrals

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Table 2

Learner Demographics

	Total (N=77) %
Ethnicity	
Hispanic/Latino	4 (5.2%)
Not Hispanic/Latino	71 (92.2%)
Participant chose not to respond	2 (2.6%)
Race *	
White	65 (84.4%)
Black/African-American	1 (1.3%)
Asian	1 (1.3%)
More than one race	6 (7.8%)
Participant chose not to respond	4 (5.2%)
Other	3 (3.6%)
Sex	
Male	0 (0.0%)
Female	76 (98.7%)
Participant chose not to respond	1 (1.3%)
Highest Degree	
Associate’s	8 (10.4%)
Bachelor’s	22 (28.6%)
Graduate	47 (61.0%)
Workplace Setting	
Academic Cancer Center	34 (44.2%)
Community Cancer Center	11 (14.3%)
University Hospital	11 (14.3%)
Community Hospital	8 (10.4%)
Private Practice	3 (3.9%)
Other	10 (12.9%)
Years in Nursing	
1–10	26 (33.8%)
11–20	20 (26.0%)
21–30	8 (10.4%)
31–40	22 (28.6%)
Participant chose not to respond	1 (1.2%)

* Respondents could choose more than one

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Table 3

Illustrative Quotes Related to Themes

Theme	Representative Quote
Concerns about Cost	"*What surprised me the most from our discussion was that most of the FP procedures were not covered by insurance, even sperm banking!*" "*I was very impressed when* [the REI] *informed that her facility offers free egg freezing to any patient with a cancer diagnosis, saving them thousands of dollars.*" "*Our institution is fortunate to have a private foundation to assist cancer patients with the cost of reproductive services. Patients must have failed one IVF cycle and meet income criteria set by the foundation. Even with this assistance, patients must still cover the fees for their initial cycle of IVF, which would be a costly process.*" "*Discounts are offered to cancer survivors through programs like Fertile Hope, but the paperwork can be daunting and not all costs are covered.*"
Challenges to Timeliness	"[Patients] *are fearful of the time delay and are so overwhelmed by the cancer diagnosis and treatment; it is difficult for them to process the complexity of ART [assisted reproductive technology] protocols.*" "*The treatment teams both pediatric and adult are so focused on cancer treatment that FP is simply not on their radar screen.*"
Lack of Information and Referrals for Patients	"*Patients continue to be unaware that there are services that can answer questions regarding their risk of infertility related to cancer treatment. Patients are unsure who to bring the subject of infertility and many times are not aware it could be an issue.*" "*Patients are not told about these services or are not interested because they don't have enough information about it.*" "*In interviewing my local REI, it was most surprising that he had only had two referrals from our oncology practice in the past,*" "*The one office saw 12 cancer patients in 2013. I was stunned (and disappointed).*" "*Dr. - shared that there were very low numbers of consultations made to an REI specialist at our facility last year. He said the majority of the time it is the patient who requests the consult.*" "*I think that one way we could change our practice is to provide a fertility packet to each family and provide them with the number to the fertility center at diagnosis so they can decide whether or not they want to have a consultation. I plan to highly suggest patients meet with a REI prior to starting cancer therapy.*"
Learning about Available Options	"*Not only does the oncologist lack time to discuss FP with their patients, but they lack training in this area as well;* [the REI] *described it as 'a whole other language to oncologists'.*" "*I found it interesting that since the publication of the textbook [provided as part of the ENRICH training program (REFERENCE REMOVED FOR ANONYMITY] that oocyte cryopreservation is now considered standard of care, and that the number of live births has increased.*" "*Most surprising to me was the discussion that new changes in technology in the past several years that make it possible to fertilize with only one sperm.*" "*I found it very interesting that someone can go to an egg bank, pick out the eggs of a person who looks similar and then proceed with IVF. I didn't realize how much choice there was in deciding which egg and sperm is used to create an embryo.*" "*One predominant feeling is that there needs to be more education about FP.*" "*Since this is a sensitive topic, we need to educate nurses and physicians on conversation starter questions, give them appropriate resources and inform them of the different options that patients have and contacts of REIs.*"

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Theme	Representative Quote
	"*I also feel we need to provide education and awareness within our own ranks, to our own attending physicians and nurse practitioners, so that discussion of FP can be incorporated into first consults and made a part of the pre-transplant evaluation.*"
	"*These families are in a 'shell shocked state' at the time of diagnosis. They have to absorb a lot of information regarding diagnosis and treatment options. Reviewing the options available, it excludes preteen patients due to invasiveness and often still experimental in nature…until newer and less invasive procedures are available, it is unlikely young children could be included as it would be difficult for parents to consent to.*"
	"*As for materials for the actual sperm donation, there are pornography magazines in the clinic but there was a question of what is really age appropriate for adolescents/young adults compared to an adult male and if this material really exists.*"
	"*The young patients haven't had a chance to think about having kids - they are made to think and grow up so much faster because of their diagnosis.*"
	"*When discussing issues surrounding adolescent patients and same sex partners, including parental decisions and allowing for legal issues can make fertility decisions more challenging.*"
	"*I believe that there is an emotional aspect especially for parents that makes anything but saving their child's life almost insignificant.*"
	"*The most common misconception faced is that female patients believe IVF treatment will affect their treatment outcomes.*"
	"*There is a disparity in pressures felt by men versus women when considering FP. Men are able to make same-day appointments for sperm banking and are not required to have a consultation. According to Dr. -, often times, male cancer patients are encouraged to come in to bank sperm and do so without giving it much thought. This is minimal compared to the process and decision making required of women.*"
	"*While sperm banking can generally be accomplished within days for men, it may take several weeks to retrieve a woman's eggs depending upon where she is in her menstrual cycle, and some oncologists might discourage a woman from waiting to begin treatment.*"